



The Honorable Jason Crow
1229 Longworth HOB
Washington, DC 20515

April 13, 2021

Dear Congressman Crow:

I am writing to express my strong support for the Community Grant Fund request submitted to your office by the Global Down Syndrome Foundation (GLOBAL) affiliate, the **Linda Crnic Institute for Down Syndrome** (Crnic Institute) at the University of Colorado.

The Crnic Institute is first, and so far only, academic home for scientific research and medical care for those with Down syndrome in the US, and it is the largest center for Down syndrome research in the world, with more than 50 research teams and over 200 talented scientists who are dedicated to elongating life and improving health outcomes for people with Down syndrome.

Led by Dr. Joaquin Espinosa, the Crnic Institute has clearly laid out the different "disease spectrum" that people with Down syndrome have whereby they are highly protected from certain medical conditions (e.g., solid tumors, certain kind of heart attacks and stroke), yet highly predisposed to others (e.g., Alzheimer's disease, autoimmune disorders, autism, blood cancers).

With the advocacy of GLOBAL and the Crnic Institute, the National Institutes of Health (NIH) understands that studying people with Down syndrome can significantly help this vulnerable and underserved population, and also help tens of millions of Americans suffering from the diseases those with Down syndrome are protected from or predisposed to.

The Crnic Institute is not only an internationally renowned resource but a local resource saving and transforming lives every day. Over the past three years alone, the Crnic Institute scientists have secured over \$40 million in new peer reviewed research funding from the NIH. These funds have attracted the best researchers to the University of Colorado Anschutz Medical Campus, launched clinical trials that are improving health outcomes, and hold promise for continued breakthrough.

Recently, Crnic Institute researchers announced a major breakthrough discovery that allows us to categorize Down syndrome as an immune system disorder. This immune dysregulation affects multiple organ systems and is observed across the lifespan. Their work on immune system dysregulation holds tremendous promise for autoimmune disorders, Alzheimer's disease and solid tumors.

To advance these efforts and accelerate this critical ground breaking research, we are asking for your support for federal funding for the Crnic Institute to acquire a state-of-art Immune Monitoring Station. Many leading academic medical centers have this equipment and this would be the only system on the entire University of Colorado Anschutz Medical Campus. I urge you to support this critical request and thank you in advance for your support.

Sincerely,

Lloyd Lewis - President and CEO of arc Thrift Stores



**COLORADO
CROSS-DISABILITY
COALITION**

1385 S. Colorado Blvd. Bldg. A, Ste. 610

Denver, Colorado 80222

303.839.1775

www.ccdonline.org

Julie Reiskin

Executive Director

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720.961.4261 (Direct)

303.648.6262 (Fax)

April 13, 2021

The Honorable Jason Crow
1229 Longworth HOB
Washington, DC 20515

Dear Congressman Crow:

I am writing to express my strong support for the Community Grant Fund request submitted to your office by the Global Down Syndrome Foundation (GLOBAL) affiliate, the **Linda Crnic Institute for Down Syndrome** (Crnic Institute) at the University of Colorado. I am writing on behalf of the Colorado Cross-Disability Coalition, the largest statewide disability rights organization in Colorado. Our mission is to advocate for social justice on behalf of people with all types of disabilities (cross-disability). We have worked with GLOBAL over the years and they have supported a variety of disability rights positions including the right to health care and voting rights.

The Crnic Institute is first, and so far, only, academic home for scientific research and medical care for those with Down syndrome in the US, and it is the largest center for Down syndrome research in the world, with more than 50 research teams and over 200 talented scientists who are dedicated to elongating life and improving health outcomes for people with Down syndrome.

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With the advocacy of GLOBAL and the Crnic Institute, the National Institutes of Health (NIH) understands that studying people with Down

NOTHING ABOUT us, WITHOUT us...EVER!

syndrome can significantly help this valuable population, and also help tens of millions of Americans living with the diseases those with Down syndrome are protected from or predisposed to.

The Crnic Institute is not only an internationally renowned resource but a local resource saving and transforming lives every day. Over the past three years alone, the Crnic Institute scientists have secured over \$40 million in new peer reviewed research funding from the NIH. These funds have attracted the best researchers to the University of Colorado Anschutz Medical Campus, launched clinical trials that are improving health outcomes, and hold promise for continued breakthrough. People with disabilities widely report that they do not feel safe or comfortable seeking medical care due to lack of cultural competency on disability issues. Facilities like the Crnic Institute provide a safe culturally competent space for a small segment of our community to seek care and a rare opportunity for members of our community to get top-notch high-quality care. We hope that this model can be replicated and used to support better care for people with all types of disabilities.

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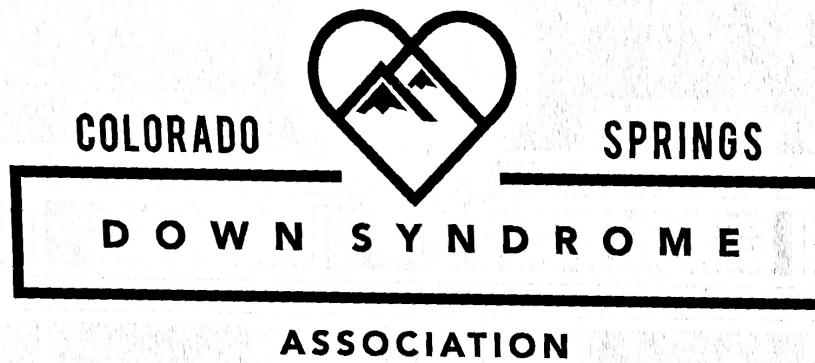
To advance these efforts and accelerate this critical ground-breaking research, we are asking for your support for federal funding for the Crnic Institute to acquire a state-of-art Immune Monitoring Station. Many leading academic medical centers have this equipment, and this would be the only system on the entire University of Colorado Anschutz Medical Campus. I urge you to support this critical request and thank you in advance for your support.

Sincerely,

A handwritten signature in blue ink, appearing to read 'Julie Reiskin', with a long, sweeping horizontal line extending to the right.

Julie Reiskin, LCSW

Executive Director



April 13, 2021

The Honorable Jason Crow
1229 Longworth HOB
Washington, DC 20515

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Sincerely,

Julie Harmon
Treasurer
CSDSA Board of Directors



April 13, 2021

The Honorable Jason Crow
1229 Longworth HOB
Washington, DC 20515

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Sincerely,

A handwritten signature in black ink, appearing to read "R. Krafczyk".

Roman Krafczyk
President/CEO

Easterseals Colorado
393 S Harlan St, Suite 250 • Lakewood, CO 80226
Phone 303.233.1666 • Fax 303.233.1028
www.eastersealscolorado.org



April 13, 2021

The Honorable Jason Crow
1229 Longworth HOB
Washington, DC 20515

Dear Congressman Crow:

We have had the honor of working closely with the Global Down Syndrome Foundation and the Linda Crnic Institute for Down Syndrome here at Make-A-Wish Colorado for many years. Over the years, we have partnered on many Wishes to support kids with Down syndrome as these kids are 5-10x more likely to have blood cancers and other critical illnesses. These wishes bring hope and joy during a difficult time, but we would love to see a day when kids with Downs syndrome are not disproportionately affected by these critical illnesses.

It is for this reason I am writing to express my strong support for the Community Grant Fund request submitted to your office by the Global Down Syndrome Foundation (GLOBAL) affiliate, the **Linda Crnic Institute for Down Syndrome** (Crnic Institute) at the University of Colorado.

The Crnic Institute is first, and so far only, academic home for scientific research and medical care for those with Down syndrome in the US, and it is the largest center for Down syndrome research in the world, with more than 50 research teams and over 200 talented scientists who are dedicated to elongating life and improving health outcomes for people with Down syndrome.

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Sincerely,

A handwritten signature in black ink, appearing to read 'SD', followed by a long, sweeping horizontal line that extends to the right.

Scott Dishong
President and CEO
Make-A-Wish Colorado



April 13, 2021

The Honorable Jason Crow
1229 Longworth HOB
Washington, DC 20515

Dear Congressman Crow:

I am writing personally as a former researcher and on behalf of The Rise School of Denver, an inclusive, nonprofit, therapeutic preschool supporting quite a few young children with Down syndrome and their families each year, to express strong support for the Community Grant Fund request submitted to your office by the Global Down Syndrome Foundation (GLOBAL) affiliate, the **Linda Crnic Institute for Down Syndrome** (Crnic Institute) at the University of Colorado.

The Crnic Institute is the first, and so far the only, academic home for scientific research and medical care for those with Down syndrome in the US, and it is the largest center for Down syndrome research in the world, with more than 50 research teams and over 200 talented scientists who are dedicated to elongating life and improving health outcomes for people with Down syndrome. Led by Dr. Joaquin Espinosa, the Crnic Institute has identified a different “disease spectrum” that people with Down syndrome have that highly protects them from certain medical conditions (e.g., solid tumors, certain kind of heart attacks and stroke) and yet highly predisposing them to others (e.g., Alzheimer’s disease, autoimmune disorders, autism, blood cancers).

The Crnic Institute is an internationally renowned resource and also a local resource as well, saving and transforming lives every day. With the advocacy of GLOBAL and the Crnic Institute, the National Institutes of Health (NIH) understands that studies focused on Down syndrome can significantly help this vulnerable and underserved population while also helping tens of millions of Americans suffering from the diseases those with Down syndrome are protected from and/or predisposed to. Over the past three years alone, the Crnic Institute scientists have secured over \$40 million in new peer reviewed research funding from the NIH. These funds have attracted the best researchers to the University of Colorado Anschutz Medical Campus where clinical trials are improving health outcomes and holding promise for continued breakthrough.

Recently, Crnic Institute researchers announced a major breakthrough discovery that allows us to categorize Down syndrome as an immune system disorder affecting multiple organ systems across the lifespan. Their work on immune system dysregulation holds tremendous promise for autoimmune disorders, Alzheimer’s disease and solid tumors.

To advance these efforts and accelerate this critical ground breaking research, The Rise School of Denver is asking for your support for federal funding for the Crnic Institute to acquire a state-of-art Immune Monitoring Station. Many leading academic medical centers have this equipment and it would be the first and only system on the entire University of Colorado Anschutz Medical Campus. I urge you to support this critical request and thank you in advance for your support.

Sincerely,

Jaclyn D. Joseph, PhD, BCBA-D, MSW
Executive Director
The Rise School of Denver



7200 E. Hampden, Suite 301
Denver, Colorado 80224

April 13, 2021

The Honorable Jason Crow
1229 Longworth HOB
Washington, DC 20515

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Sincerely,

A handwritten signature in blue ink that reads "Mary Ann Barwick". The signature is fluid and cursive, with the first name "Mary" and last name "Barwick" clearly distinguishable.

Mary Ann Barwick

Executive Director

Rocky Mountain Down Syndrome Association



April 20, 2021

The Honorable Jason Crow
1229 Longworth HOB
Washington, DC 20515

Dear Congressman Crow:

I am writing to express my support for the Community Project Funding request submitted to your office by the Global Down Syndrome Foundation (GDSF) in support of research at the Linda Crnic Institute for Down syndrome (Crnic Institute) at the University of Colorado's Anschutz Medical Campus.

The work of the Crnic Institute and GDSF continues to be a locus of enormous scientific progress and opportunity on our campus. The Crnic Institute is the largest center for Down syndrome research in the world, with more than 50 research teams and over 200 talented scientists. Over the past several years, faculty at the Crnic Institute have secured over \$40 million in new, peer-reviewed research funding from the National Institutes of Health. These funds – combined with prior support from the GDSF -- are attracting elite scientist to CU Anschutz and supporting a dynamic and growing research community.

Much of this excitement and activity is due to an increased commitment from NIH to fund Down syndrome research. That increase is due in no small measure to the passion and ingenuity of Michelle Sie Whitten and the Global Down Syndrome Foundation. Her efforts to persuade NIH and Congress of the scientific opportunities and moral imperatives found in funding Down syndrome research have done nothing less than change this field of science as we know it.

Despite these NIH investments in research support, a significant need persists at the Crnic Institute around funding for highly specialized research equipment that is capable of answering the complex and intriguing scientific questions being raised by this new, nation-wide research effort. Recently, Crnic Institute faculty announced an important discovery that many common differences in health outcomes for individuals with Down syndrome are the result a chronic dysfunction of the immune system. Understanding how the immune system affects the appearance and development of these differential health outcomes holds the promise of translating this science into meaningful results for patients with a variety of conditions from Down syndrome to cancer to Alzheimer's disease.

To advance these efforts and accelerate this critical ground-breaking research, we support the GDSF request to acquire a state-of-art Immune Monitoring Station for the Crnic Institute. This financial support will help ensure Colorado's continued national leadership in this field of research and will also help us improve the lives of patients everywhere.

Sincerely,

A handwritten signature in black ink, appearing to read 'Donald M. Elliman, Jr.'.

Donald M. Elliman, Jr.
Chancellor

Joaquín M. Espinosa, PhD

Anna and John J. Sie Chair in Genomics
Executive Director, Linda Crnic Institute for Down Syndrome
Professor, Department of Pharmacology
Director, The Functional Genomics Facility
University of Colorado School of Medicine

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espinosalab.org | trisome.org | crnicinstitute.org



April 13, 2021

The Honorable Jason Crow
1229 Longworth HOB
Washington, DC 20515

Dear Congressman Crow:

As the Executive Director of the Linda Crnic Institute for Down Syndrome at the University of Colorado, I am writing to ask for your support for a Community Grant Fund request to acquire a state-of-art Immune Monitoring Station that will be used by researchers at the Crnic Institute and across the Anschutz Medical Campus to pursue important cutting-edge science.

Prior to the Crnic Institute's founding in 2008, the National Institutes of Health awarded very few research grants to study Down syndrome and there was little scientific interest in understanding why having an extra copy of chromosome 21 protects this population from developing certain diseases and while predisposing them to others. In a little over a decade, the University of Colorado is now home to the largest center for Down syndrome research in the world, with more than 50 research teams and over 200 scientists. Our internationalized recognized scientific center is significantly advancing the understanding of this genetic condition, aiming to decipher why individuals with Down syndrome have a different 'disease spectrum' relative to the general population, being protected from some medical conditions (e.g., solid tumor, certain kind of heart attacks and stroke), but highly predisposed to others (e.g., autoimmune disorders, autism, Alzheimer's disease). Our ultimate goal is to improve health outcomes in this population through novel therapeutics and diagnostics.

This instrumentation will cement the leadership position of the Crnic Institute in the field of immune dysregulation in Down syndrome by enabling Crnic Institute scientists and their collaborators to do better science faster. Crnic Institute scientists currently hold the largest amount of NIH dollars for the study of the immune system in Down syndrome, including grants from NIAID, NIAMS and NHLBI. In fact, Crnic Institute scientists have already translated their discoveries into a first-in-kind clinical trial for immune modulation in Down syndrome funded by NIAMS, which is currently active and recruiting. Funding for the Immune Monitoring Station will enable Crnic Institute scientists to renew these important grants, secure considerable new grant funding, and multiply the impact of this financial investment at the University of Colorado Anschutz Medical Campus, the University of Colorado Boulder, and most importantly in scientific research benefiting the 7-8 million people with Down syndrome across the world.

Crnic Institute scientists recently made a breakthrough discovery that much of the differential disease spectrum in people with Down syndrome could be explained by chronic dysfunction of

the immune system. This immune dysregulation affects multiple organ systems and is observed across the lifespan. Understanding how the immune system affects the appearance and development of the comorbidities of Down syndrome would also benefit the general population affected by these same conditions.

Within this context, our request for an Immune Monitoring Station aims to equip scientists with state-of-art equipment that will enable a deep and comprehensive characterization of the immune system of individuals with Down syndrome with and without diverse comorbidities. It will include a) an automated liquid handling system for high-throughput processing of blood samples, b) a spectral flow cytometer for detailed quantification of hundreds of immune cell types in the bloodstream and tissues, c) a high-performance data storage and computing system for analysis of high-dimensional flow cytometry data, and d) a long-term cryopreservation system to store blood samples and their subcomponents.

This Immune Monitoring Station will significantly accelerate the pace of discoveries in the field of Down syndrome research by enabling a deep characterization of the immune abnormalities that predispose individuals with Down syndrome to a variety of comorbidities tied to their chronic inflammatory state, including but not restricted to transient myeloproliferative disorder, lymphocytic and myeloid leukemias, autoimmune thyroid disease, autoimmune skin diseases, celiac disease, seizure disorders, developmental regression, autism spectrum disorder, pulmonary hypertension, dysphagia/aspiration, and Alzheimer's disease.

The Immune Monitoring System will be one of the most heavily used pieces of equipment at the Crnic Institute specifically, but also at the University of Colorado Anschutz Medical Campus more broadly. The primary users would be intramural scientists at the Crnic Institute and their collaborators across the Crnic Institute's portfolio of grantees and NIH-funded scientists. Priority will be given to studies focused on the immune aspects of Down syndrome, but the instrument will be made available to other scientists at other divisions and departments at the Anschutz Medical Campus performing research on the immune system.

The impact of this instrumentation will be tremendous, as it will enable high throughput analyses of blood samples at an unprecedented scale. To give an example, the last immune monitoring effort of ~400 samples from individuals with Down syndrome performed at the Crnic Institute took nearly a year to complete, as it required the use a different, low throughput system shared by the entire campus for which Crnic Institute scientists could book a single day a week. The new station would have expedited this process ~10 fold.

To advance these efforts and accelerate this critical ground-breaking research, we are asking for your support for federal funding for the Crnic Institute to acquire a state-of-art Immune Monitoring Station. Many leading academic medical centers have this equipment and this would be the only system on the entire University of Colorado Anschutz Medical Campus. I urge you to support this critical request and thank you in advance for your support.

Sincerely,

A handwritten signature in blue ink, appearing to read 'Joaquin M. Espinosa', with a stylized flourish at the end.

Joaquín M. Espinosa